EQUITY AND EXCELLENCE: LIBERATING THE NHS

Response to the White Paper

The Afiya Trust
27-29 Vauxhall Grove
London
SW8 1SY

Contact:
Patrick Vernon, CEO
Tel: 02075820400
Email: Patrick.vernon@afiya-trust.org

The Afiya Trust is a national second tier organisation with an England-wide remit to reduce inequality in health and social care provision for racialised communities. We host several networks that bring together service users, carers, professionals, academics and community members who are concerned about health and social care provision and want to see positive changes. Over the years our work has focused on mental health, cancer, stroke and other health issues, on service user and carer concerns, and on promoting the wellbeing of England's diverse communities. We host the National Black Carers and Carers Workers Network, the National BME Mental Health Network, Catch-a-Fiya Mental Health Service User and Carer Network, and the National BME Mental Health Advocacy Network. Through our networks we have access to around 1000 individuals and organisations, and their views and opinions inform our work and policy.

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The Afiya Trust welcomes the opportunity to respond to the Government's White Paper *Equity and Excellence: Liberating the NHS*. Our response is informed by on-going debates and discussions within the black and minority ethnic (BME) community and voluntary sectors, including a mapping of health and social care organisations, and consultations we undertook in the context of this White Paper. In that sense, this response represents not only Afiya's specific views, but those of our allies and stakeholder groups.

We welcome the proposals to put patients and public at the heart of healthcare and to devolve power from the centre to local areas. These are in many ways in tune with what BME communities have campaigned for over a long period of time. The proposals to increase access to information and choice are also in tune with what the communities have been asking for. The Equality Impact Assessment (EIA) of the White Paper acknowledges that inequalities exist in access to information, awareness of choice, pathways into care, satisfaction with GP and other services, and health outcomes.

However, we are concerned that details about how the new structures and processes will address race equality and ensure that the specific needs of ethnic minority communities are met are unclear. It is also not clear what structures and mechanisms will be put in place to ensure that the voices of those most marginalised in society are heard within patient and public involvement processes.

On the ground, the White Paper and its proposals are being read in the context of widespread cuts in spending. The BME health and social care and community organisations have traditionally suffered from the lack of sustainable funding and resources, even as mainstream organisations have by and large failed to address the specific needs within communities. The details of spending cuts so far do not bode well for this sector. If now there is an invitation is to be fully involved in local decision making and in our own care and wellbeing, the BME sector and community organisations need to be fully resourced and supported.

PUTTING PATIENTS AND PUBLIC FIRST

"No decision about me without me" is a noble and essential ideal and it is gratifying to see that the White Paper makes a commitment to this. However, there is enough evidence to show that many minority ethnic communities have poor access to health and social care services for a variety of reasons including language barriers, lack of awareness and information, social isolation, lack of culturally sensitive services and negative attitudes about communities. Service users and carers from minority ethnic communities are dissatisfied with the opportunities, modes and levels of influence they have in mainstream user involvement activities

Our Recommendations:

- The new consumer champion, HealthWatch England, has a mandatory duty to include and involve diverse communities, especially those who are marginalised, and to publish a race equality scheme
- Conduct a review of LINKs to learn whether they have been successful in involving BME communities and incorporate the findings while establishing HealthWatch
- Evaluate the functioning of HealthWatch, both at local and national levels, against involvement standards set by service users and carers from diverse communities

Improving Healthcare Outcomes

We welcome the Government's commitment to reduce mortality and morbidity, increase safety, and improve patient experience and outcomes for all. As we know from decades of evidence, there are continuing disparities in health and social care outcomes for people from many minority ethnic communities. The EIA of the White Paper has noted evidence from GP surveys to show that people from some minority ethnic communities are less likely than white people to be satisfied with services from their GP. Multiple marginalisation (for example, of older people from BME communities, of refugee, asylum seeker, gypsy/traveller communities, of BME LGBT people, of mental health service users) can have significant negative outcomes on health which are not always picked up by mainstream service provision.

Our Recommendations:

- Set mandatory duty on all providers for accountability on health equality outcomes through:
    - Setting milestones to end racial inequalities in health and social care
    - Commissioning a yearly independent report on race inequalities in health and social care
- Outcome measures against which NHS will be held accountable should be based on the specific needs of communities. One size does not fit all.
- BME service user and carer leadership should be at the heart of setting quality standards. This means setting up structures to increase their influence within NICE.
- Performance standards against which providers will be paid should reflect the idea of holistic health. BME organisations and community groups must have a key role in setting these standards.

Autonomy, Accountability and Demographic Legitimacy

The Government's resolve to devolve power and responsibility for commissioning services through GP Consortia is perhaps the most troubling for BME communities. Consistent evidence through GP surveys has shown that BME communities face significant problems in access to culturally appropriate services and information. There are also concerns about the ability and readiness of GPs to be in charge of commissioning services. This is more so in the context of services where BME communities have faced consistent inequality and overrepresentation, like mental health services. A recent survey by Rethink showed that only 31% of the GPs surveyed felt ready to take on commissioning responsibilities for mental health services.

It is heartening to see that the NHS Commissioning Board will have an explicit duty to promote equality and tackle inequalities in access to healthcare. The duty can translate into action only by creating partnerships with communities and organisations who, we believe, hold the knowledge about what works for them.

Our Recommendations:

- Local BME organisations are given a key role in up-skilling GPs to take on this new role through training in race equality awareness and competency and in how to involve local communities in decision making
- The NHS Commissioning Board has a race equality task group to advise and influence commissioning processes and requirements
- The NHS Commissioning Board make a clear commitment to cross-borough commissioning to meet the needs of smaller, dispersed minority ethnic communities

Cutting Bureaucracy and Improving Efficiency

While it is imperative that systems and structures are revamped to increase efficiency and value for money in times of financial crisis, this should not be at the cost of losing transparency and accountability.

Our Recommendations:

- Efficiency cuts do not disproportionately affect BME communities and their organisations
- Culturally appropriate services, set up to fill the gaps in mainstream service provision, are not affected in the move to streamline services. This will have the detrimental effect of removing existing support systems from those who need them most
- Cost efficiency and value for money are assessed based on how well a given service is meeting the needs of the local communities, especially those marginalised from mainstream service provision.

In Conclusion

In March 2010, the Afiya Trust published *Achieving Equality in Health and Social Care: A Framework for Action*, based on consultations with our networks which elicited over 500 responses. The key recommendations from this document remain highly relevant in the context of the proposed changes to the NHS if these changes are to be equitable.

We believe that it is not possible to achieve better health and wellbeing for all without addressing the specific needs of our diverse, minority ethnic communities. BME-led organisations, nationally, regionally and locally, hold the knowledge on what these needs are and the expertise on how to address them. It could be argued that BME communities and their organisations have been "doing" the Big Society for decades now, working against a backdrop of resource constraints, unsustainable funding, and changing policy focus.

We hope that while providing more details about how the ideals in the White Paper will work in practice, the Government will take into account the recommendations we have made and commit to a real partnership with the BME communities and organisations representing these communities.